

Together We Are...Making an Impact

on Education, Connection, and Advocacy
for Health Outcomes and Well-Being
Among Women Living with HIV

THE WELL PROJECT SURVEY REPORT

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and Advocacy on Health Outcomes and Well-Being Among Women Living with HIV

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Introduction

Dedication

The Well Project team and Board of Directors would like to dedicate this report to the 239 participants (including 157 women living with HIV) who spent their valuable time sharing information about their lives, as well as the use and effectiveness of The Well Project's resources.

We also dedicate this report to the 18 million women living with HIV around the globe who overcome structural and interpersonal challenges every day. These women exhibit resilience, despite numerous barriers, organize our communities, advocate for access to healthcare and HIV treatment, raise families, and change policy and laws. This work is also dedicated to the millions of people who have died not only due to health complications from HIV, but also as a result of HIV stigma and discrimination.

Thanks

We would like to extend our thanks to all of the individuals whose hard work and commitment made the development, implementation, and analysis of this survey possible. Specifically, we thank Community Advisory Board (CAB) members: Gina Brown, Kimberly Canady, Jyoti Dhawale, Aryah Lester, Arianna Lint, Tiommi Jenae Luckett, Vickie Lynn, Maria Mejia, Abosede Olotu, Wanona Thomas, and Masonia Traylor for their invaluable contributions.

We would also like to thank our team of advisors who played critical roles in the development of the survey, analysis, and report, including Judith D. Auerbach, PhD, Vignetta Charles, PhD, Jenna Conley, E. Maxwell Davis, PhD, Olivia G. Ford, Krista Martel, Seow Ling Ong, and Sweet Potato Design.

Finally, we thank the funders, without whom this work would not have been possible: Gilead Sciences, Inc., Janssen Therapeutics, Merck, and ViiV Healthcare, as well as the many individual donors who contributed to The Well Project. We are deeply grateful for all of your input, guidance, and support.

Background

The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. Founded in 2002, The Well Project is the premier online resource on women and HIV both nationally and globally, reaching more than three million users annually through our web portal and social media channels. The Well Project leverages technology to dramatically improve health outcomes and quality of life for women living with HIV. The information and community support that The Well Project offers

help women build a foundation to not only survive but also thrive with HIV. Through our programs and resources, we facilitate the movement of our constituents along a trajectory from education to community connection to advocacy that gives them agency to act on their own behalf and on behalf of their communities.

In order to maximize The Well Project's effectiveness and continuously strengthen the impact of our programs, we seek to understand how our resources and services are experienced, integrated, and applied by those utilizing them. One method we use to gather this information is periodic user surveys. Historically, these surveys have shown us that individuals accessing The Well Project's online resources are looking to secure accurate and relevant information about HIV disease and treatment and connect to women around the world. We also have learned that accessing these resources has broken down barriers to HIV testing and supported our users as they engage in HIV care and treatment.

"I think The Well Project does a phenomenal job of providing resources to all women. It's one of the best places available for female-centric info on HIV and AIDS, and I'm grateful to have access to it."

For each survey, we develop and implement questions to assess our current reach and impact and identify areas for improvement and enhancement. This report provides a descriptive analysis of findings from the 2018-2019 online user survey. **While respondents represented diverse genders and HIV serostatuses, our primary constituents are women living with HIV, inclusive of transwomen, so the report primarily describes findings from this group.** Our analysis focuses on factors influencing the lives of women living with HIV and the impact of The Well Project's online resources on their engagement with healthcare, HIV-related self-care, outlook on living with HIV, community connection, and advocacy.

Our survey data highlight some of the opportunities and challenges for women along and beyond the HIV care continuum. In particular, they make clear the need to expand notions of optimal outcomes beyond viral suppression (i.e., have an undetectable viral load) to include measures of broader health and quality of life as articulated by women themselves based on their **lived experiences**. This refers to attending to "knowledge gained through direct, first-hand involvement in everyday events, rather than through representations constructed by other peopleⁱ." Such "everyday events" include women's interactions with the HIV care system, but also interactions with other medical, psychological, social, and environmental factors that influence how they understand, feel, and act in relation to their diagnosis in the broader context of their lives. Our survey offered respondents the opportunity to convey these experiences in their own words, and to tell us how The Well Project's resources relate to them and facilitate their movement along the education-connection-advocacy trajectory.

ⁱ Oxford Reference: <https://www.oxfordreference.com/view/10.1093/oi/authority.20110803100109997>

Methods

The Well Project's 2018-2019 user survey was developed by The Well Project staff and CAB, with input from a research consultant and a member of the Board of Directors. The survey was administered through the SurveyMonkey platform and included both closed- and open-ended questions. Recruitment of survey participants began in October 2018 and continued through February 2019. Information about the survey was posted to The Well Project's website, included in e-newsletters, and circulated on various social media channels. The Well Project's CAB, Board of Directors, and community partners were encouraged to disseminate recruitment materials to their networks (including social media), and professional and personal contacts. They also conducted in-person survey events. All recruitment materials included embedded survey links.

A total of 369 surveys were completed. Data cleaning and a quality check were undertaken to eliminate duplicate and incomplete responses. As a result, the final sample included 239 respondents or 65% of the raw data sample. Of these, 157 (66%) self-identified as women living with HIV—both cis and trans. (Note, the survey did not explicitly specify “cisgender” as an option, therefore cisgender will not be used throughout this report.) ***As women living with HIV are the primary constituency of The Well Project, the majority of the analysis in this report focuses on them.***

Key domains for analysis reported below included:

- Characteristics of the women living with HIV sample
- Experiences of women living with HIV along the care continuum
- Factors influencing the health and well-being of women living with HIV, including HIV stigma, disclosure of HIV status, concurrent health conditions, mental health and trauma, and impact and awareness of U=U
- Use and assessment of The Well Project's online resources
- Assessments of the impact of using The Well Project's resources on users' own HIV knowledge, engagement in care, self-care, outlook on living with HIV, connection and collaboration, and engagement in advocacy

Characteristics of the Women Living With HIV Sample



As seen in Table 1.1, among the total 157 women living with HIV, 92% self-identified as women and 8% self-identified as transwomen. (Note that the survey did not explicitly specify “cisgender” as an option, therefore cisgender will not be used throughout this report.) The vast majority (86%) identified as heterosexual, 8% as bisexual, 5% as gay, lesbian, or queer, and 1% as pansexual.

TABLE 1.1

Key Identity Features of Women Living with HIV (n=157)	
Age (Average)	49.1
19 to 29	6%
30 to 39	15%
40 to 49	27%
50 to 59	28%
60 or older	24%
Gender Identity	
Woman	92%
Transwoman	8%
Sexual Orientation	
Heterosexual	86%
Gay, Lesbian, or Queer	5%
Bisexual	8%
Pansexual	1%
Race and Ethnicity	
Aboriginal, Native, or Indigenous	1%
African, African Descent, or Black	47%
Asian, East Asian, or Pacific Islander	0.6%
South Asian or Indian	0.6%
Southeast Asian	-----
Caucasian, Non-Hispanic White	34%
Hispanic or Latinx	13%
Middle Eastern or Arab	-----
Multiracial	3%

Our sample was diverse in age, although it skewed toward mid-life and older women. The average age of respondents was 49 years. 51% were 50 years or older, 43% were between 30 and 49, and 6% were between 19 and 29.

Nearly half (47%) of the sample identified as African, of African descent, or Black; 34% as Caucasian, non-Hispanic white; 13% as Hispanic/Latinx; 2% as Multiracial; 1% as Aboriginal, Native, or Indigenous; and less than 1% as Asian, East Asian, or Pacific Islander.

The overwhelming majority (86%) of respondents reported living in North America, followed by 8% in Africa. Five respondents lived in Central America/Caribbean, three in Europe, and two in Asia. Across regions, nearly two-thirds (63%) lived in urban areas, 24% in suburban areas, and 13% in rural areas (Table 1.2).

TABLE 1.2

Geography Characteristics of Women Living with HIV (n=157)	
Global Location	
Africa	8%
Asia & South Asia	1%
Central America & Caribbean	3%
Europe	2%
North America	86%
Residential Setting	
Urban	63%
Suburban	24%
Rural	13%

As seen in Table 1.3, our sample was an educated group. More than half of the respondents (57%) continued past high school, with 29% indicating that they have a college or graduate degree. Notwithstanding their educational attainment, respondents had low levels of employment and lived in households with relatively modest incomes. 28% reported being employed full-time, 18% were employed part-time, 13% were unemployed, 10% were retired, 2% were homemakers, and 29% had a medical disability and were unable to work.

Data in Table 1.4 show that more than two-thirds (76%) of respondents had household incomes of less than \$40,000 per year, including 50% with incomes of less than \$20,000 per year.

TABLE 1.3

Education and Employment Status of Women Living with HIV (n=157)	
Level of Education	
Less than high school	12%
Some high school	5%
High school or equivalent	36%
Some college/ 2 year degree	28%
College/ 4 year degree	16%
Graduate degree	13%
Paid Employment Status	
Employed full time	28%
Employed part time	18%
Unemployed/ seeking work	12%
Unemployed/ not seeking work	1%
Homemaker	2%
Retired	10%
Disabled/ unable to work	29%

The largest proportion of respondents—34% overall and 54% of transwomen—were renters, 29% were homeowners, 20% live in subsidized housing, 11% depended on family and friends for their living situations, and 5% had no permanent housing. More than half of our sample either lived alone (29%) or with one other person in the same household (33%), and 38% were caring for young children and/or adults.

TABLE 1.4

Household Characteristics of Women Living with HIV (n=157)

Household Income	
\$0 - \$19,999 per year	50%
\$20,000 - \$39,999 per year	26%
\$40,000 - \$59,999 per year	12%
\$60,000 - \$79,999 per year	5%
\$80,000 - \$99,999 per year	0.6%
\$100,000 or more per year	3%
Can't calculate in USD	5%
Housing Status	
No permanent housing	5%
Supported/ assisted living	1%
Subsidized housing	22%
Depend on family/ friends	11%
Rent housing	34%
Own housing	29%
Household Size	
One person	29%
Two people	33%
Three people	16%
Four people	10%
Five people	6%
Six people	7%
Household Caregiving	
Care for minor child/ren	31%
Care for adult/s	3%
Care for child/ren & adult/s	5%
No caregiving	62%

Experiences of Women Living with HIV Along the Care Continuum

The HIV care continuum (also known as the “treatment cascade”) is a useful way of monitoring and reporting progress in efforts to ensure that all people with HIV are aware of their HIV status, become engaged in HIV care and treatment, and achieve optimal health benefits from that treatment. The primary health benefit measured in the continuum is viral suppression, as this not only improves the well-being of the individual with HIV but also eliminates the chance of that individual sexually transmitting the virus to others (it also diminishes the chance of HIV transmission through other modes and research is currently underway to quantify that reduction). Our survey included questions about various stages of the HIV care continuum.

HIV DIAGNOSIS: The amount of time respondents have been living with HIV ranged from two years to 41 years, with an average of 18 years. Almost half of our sample (45%) has been living with HIV for at least 20 years (diagnosed in or before 1998). About one-quarter (26%) were diagnosed in the past 10 years, and 8% were diagnosed in the past five years.

USING HIV MEDICATIONS: Almost all (99%) of respondents reported that they were currently taking HIV medications. The average length of time on HIV medications was 16 years. The earliest year anyone reported beginning to take HIV medications was 1985, and the most recent was 2016. The one respondent who was not currently taking HIV medications indicated that she decided for herself that she did not need HIV medications.



Taking HIV Medications

99% of women living with HIV respondents reported currently taking HIV medications

ENGAGEMENT IN CARE: Almost all (98%) of respondents indicated that they were currently seeing a healthcare provider to manage their HIV. The overwhelming majority of respondents (73%) identified an HIV or infectious disease doctor as their main care provider, 11% identified a primary-care physician or family practitioner, and 3% identified a nurse practitioner. About 12% of the sample identified themselves as their main HIV care providers.



Engagement in Care

98% of women living with HIV respondents reported currently seeing a healthcare provider to manage their HIV

VIRAL SUPPRESSION: 85% of the respondents indicated that their viral loads were undetectable at last testing. Another 7% were not sure of their viral loads, and 4% chose not to disclose. When respondents (n=11) who were unaware of their viral load were asked about the reasons for this, their answers included: not being informed of their results by the clinic; not remembering their results; not seeing the doctor for two months; not taking their medications properly and developing resistance; and being out of care because the doctor relocated.



Beyond the Care Continuum: Factors Influencing the **Health and Well-Being** of Women Living with HIV

While our surveys measure the impact of The Well Project's programming, they also provide us with the opportunity to gather data on other important factors influencing women living with HIV. One of the most important overall findings from The Well Project 2018-2019 survey, much like our 2016 survey, is that women do not believe that achieving viral suppression is the most important or only measure of how they are faring with HIV disease. There are a number of other social, psychological, and medical factors that influence their HIV-associated health, overall well-being, and quality of life.

Building on the knowledge we gained from our 2016 survey showing that HIV stigma, mental health, and trauma continue to be major factors for women, our 2018-2019 survey collected additional data on these concepts. Based on guidance from our stakeholders, including our CAB, we also collected data around disclosure of HIV status, concurrent health conditions, and the awareness and impact of U=U (undetectable = untransmittable: the scientifically proven fact that people who consistently take HIV medications and maintain viral suppression cannot sexually transmit HIV to their partners). Each of these is described below.

HIV Stigma

Regrettably, HIV stigma remains an ongoing and significant presence among most women living with HIV, manifesting in multiple dimensions. We examined the impact of stigma from a variety of angles including:

- Stigma in the personal lives of women living with HIV
- Stigma experienced in healthcare settings
- Self-stigma (internalized stigma)
- Stigma experienced by friends and family members of women living with HIV

Only
16%
of women living with HIV
reported **NOT** experiencing
any stigma in their lives



“My husband committed suicide and my in-laws and neighbors would not want to talk to me or come to my home because I had lost weight they said I had HIV and that I was going to die. They believed I was the cause of my husband’s death [and] therefore no man would want his wife to come near me.”

One in two respondents overall and 85% of transwomen respondents reported having experienced stigma in either or both healthcare settings and other aspects of their lives. Only 16% of women living with HIV reported not experiencing any stigma in their lives.

PERSONAL LIVES: More than two-thirds (69%) of women living with HIV reported experiencing HIV stigma in their personal lives, including 50% who reported experiencing HIV stigma from their family members. Respondents described being shunned by family members, accused of malicious intentions, being asked to move or leave a job, and facing legal action in relation to seeing children or grandchildren—all due to HIV stigma.

***“At a place I volunteered, as a cook, community kitchen.
When they found out, they accused me of stealing and forced me out.”***

STIGMA IN THE PERSONAL LIVES OF WOMEN LIVING WITH HIV

69% (n=104) of women living with HIV reported experiencing HIV stigma or discrimination in their personal lives



50%
From family
members



49%
From
friends

41%
In their
neighborhoods



42%
At their places
of employment



39%
With romantic
partners



22%
In online forums/
chats/groups



19%
At places
of worship



16%
At HIV service
organizations



14%
At school



11%
In detention,
jail or prison



***“My daughter-in-law took me to court to keep me and my AIDS away from
any future grandchildren.”***

HEALTHCARE SETTINGS: Notwithstanding tremendous advances in HIV care and treatment, including evidence demonstrating that people on treatment with sustained viral suppression cannot sexually transmit HIV, stigma remains a major issue in healthcare settings, and was reported by 61% of respondents. Women living with HIV described numerous ways in which various healthcare providers refused to provide services, violated patient confidentiality, and imposed judgment on their behaviors.

“The staff was a friend of my husband’s family. She saw me in the office and told his daughter that I was there. HIPAA violation!! It caused so much trouble in my family.”

STIGMA EXPERIENCED IN HEALTHCARE SETTINGS BY WOMEN LIVING WITH HIV

61% of women living with HIV reported personally experiencing stigma in a healthcare setting



38%
Registered nurses
and Nurse
practitioners



35%
Healthcare
staff



32%
Emergency
department
physicians



30%
Dentists



28%
Physician
assistant/
Nursing
assistant



25%
Primary-care
physicians



19%
OB/GYNs



19%
Community
health/
Clinic worker



16%
Social
workers



12%
Case
manager



8%
Home
healthcare
worker

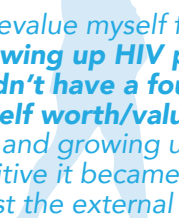
“I had been struggling with adherence to treatment last year and wasn’t on anything. A new nurse badgered me with questions, then left the room, stood in the HALLWAY and told another staffer she didn’t understand how I was supposed to be an advocate but I wouldn’t take my meds.”

SELF-STIGMA: One of the most discouraging aspects of stigma revealed by survey respondents was the level of self-stigma, meaning holding negative beliefs about HIV and stigmatizing themselves as a result of those beliefs. 60% of women living with HIV reported experiencing self-stigma. Women mentioned feeling ashamed, dirty, worthless, embarrassed, damaged, and unlovable because of their HIV diagnosis and often these feelings are reinforced by their experiences in healthcare settings and with society as a whole. While these feelings derived from the perceptions and stigma of others, respondents had internalized them to the extent that they affected how they lived their lives and thought about their relationships with others.




60%
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self-stigma

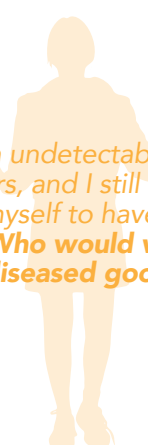
SELF-STIGMA EXPERIENCED BY WOMEN LIVING WITH HIV



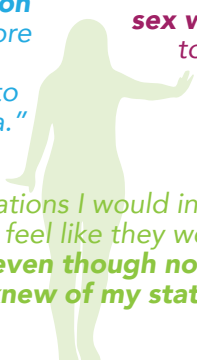
"I devalue myself frequently. Growing up HIV positive I didn't have a foundation of self worth/value before HIV and growing up HIV positive it became hard to resist the external stigma."




"I [felt] shamed because I thought that people would think that I was nasty and that I was having sex with anybody. I was scared to hold people's hands."



"I've been undetectable for 20 years, and I still can't bring myself to have sex. Who would want diseased goods?"



"In conversations I would internalize comments and feel like they were directed towards me, even though no one in the room knew of my status."



"At times I thought I was unworthy of love or sex due to having the virus."

STIGMA EXPERIENCED BY FAMILY AND FRIENDS: Not only do women living with HIV experience stigma directly, many also see that stigma extended to their loved ones. About one-third of respondents reported that their family members, children, partner(s), or spouses experienced stigma or discrimination because of the respondent's HIV status. Women living with HIV described their children being shunned at school and being excluded from family gatherings, their partners being ridiculed by others, and their relatives being forced out of work. This reality explains why some people hide their HIV status and strive to avoid sharing their status with others.



1/3
of women living with HIV
reported family members
experiencing stigma
because of the
respondent's
HIV status

STIGMA EXPERIENCED BY FAMILY MEMBERS OF WOMEN LIVING WITH HIV



*"My brothers in-law and our neighbors **would not allow their children to play with mine** because their father committed suicide and because I was thin I must have had HIV. My children would be told to the face by the other children. Every time they would come home crying."*



*"My son was **put out of daycare** because of my status."*



*"My mother's husband **used to talk bad about me saying I'm an AIDS infected B*B%**. My sister's ex-boyfriend would throw it in her face during arguments: 'That's why your sister has AIDS and is going to die from it.'"*



*"My **partner's family pushed him to divorce me**, but we have lived three years as a discordant couple."*

Disclosure of HIV Status

Remarkable advances have been made in HIV treatment in recent years, so that now a person diagnosed with HIV can live a long and healthy life and, with an undetectable viral load, will not transmit HIV to their sexual partners.

Yet, disclosing (sharing/telling) one's HIV status remains a controversial choice. While HIV disclosure can be liberating, facilitate connections with others, and enable advocacy on behalf of people with HIV, it can also be risky, and can expose women living with HIV to violence, stigma, and even criminalization.

Respondents were asked to indicate with whom they would feel comfortable disclosing their HIV status and were able to check one or more of nine available options. 95% said they were comfortable sharing their status with at least one person in their life. Only 5% of respondents indicated that there was no one to whom they would feel comfortable disclosing their HIV status. On average, respondents selected five categories of people in their lives they would be comfortable with; 24% selected all nine available options. The most frequent option was "other people living with HIV," which was selected by 72% of respondents. This highlights the importance of the HIV community connection for these women.

WOMEN LIVING WITH HIV

reported being comfortable disclosing their status to the following people in their lives

Other people living with HIV	72%
Partner(s)/spouse	68%
Immediate family members (Parents, grandparents, brothers, sisters)	68%
Close friends	67%
Audiences (for educational purposes)	58%
Child/ren	55%
Extended family members (Aunts, uncles, cousins)	52%
Casual friends	35%
Acquaintances	32%
No one	5%

Women living with HIV also articulated the top reasons for feeling comfortable or uncomfortable about disclosing their HIV status. The most common reasons for being comfortable with disclosure were to decrease stigma, to educate and empower others, and to express one's agency. A number of respondents linked their comfort disclosing to the length of time they have been living with HIV.

The most prevalent reasons women living with HIV listed for feeling uncomfortable disclosing their HIV status were stigma (including self-stigma), discrimination (i.e., at work, church, community), self-preservation, violence, and fear of rejection by family, friends, and community members. Many also cited the lack of proper HIV education and high levels of ignorance around HIV disease and its treatment.



REASONS WOMEN LIVING WITH HIV DISCLOSE THEIR HIV STATUS:

"Because there is no proxy for me! My authentic story will save lives, eradicate stigma, and will encourage others to find their voice."



*"I have lived with this more than half of my life now and it's not going away any time soon. **I have no shame about it** and have accepted my diagnosis fully a long time ago. And by being public I can educate others."*



*"After 30 years, I've gotten better at it. **And now I'm not contagious!** I like telling people they don't have to be scared of me."*



*"Because **it doesn't change WHO I am.**"*

REASONS WOMEN LIVING WITH HIV DO NOT DISCLOSE THEIR HIV STATUS:

"I am not comfortable telling potential partners for fear of rejection. I am pretty much abstinent from sex."



*"If I know someone has a negative outlook on HIV after being given information, I choose not to disclose my status. If the person is not a potential sexual partner, **for the sake of my mental peace, I keep my status to myself.**"*



*"I've disclosed in the past to family members and friends **who have decided not to have any further contact with me.**"*




*"**I don't disclose at work.** It's a small town and I run a retail store. The knowledge could hurt the store's business."*

Concurrent Health Conditions

People living with HIV experience various comorbidities, coinfections, and complications (CCC), particularly as they age. CCCs can be physical, mental, or both, and include such things as cancer, diabetes, heart disease, mental illness, and substance use disorders. Ongoing research is attempting to identify the relative influence of long-term HIV disease, long-term use of HIV medications, and normal aging processes on the manifestation of CCCs, including any sex and gender differences. Because a large proportion of our survey respondents were over 50 years old, our data may help inform this research agenda as it relates to women specifically.

About two-thirds (65%) of women living with HIV respondents indicated that they experienced other serious physical health conditions, in addition to HIV. The average age of respondents who experienced other serious health conditions was 51, compared to 45 for those who did not experience any other serious health conditions. On average, respondents indicated living with 1.5 health conditions in addition to HIV.

65% of women living with HIV indicated they experience other serious health conditions, in addition to HIV



Most commonly cited were high blood pressure (55%), asthma (28%), and diabetes (21%). When asked to list their most pressing health concern besides HIV, respondents identified mental health/depression, dealing with weight gain, arthritis, sleep disorders, and kidney issues, among others.

Mental Health and Trauma

Mental health is a very important factor in the lives of women living with HIV. It affects and is affected by HIV, overall health, well-being, and quality of life. There are multiple aspects of mental health, including behavioral health issues—such as alcohol and drug use and sexual activity—and experiences of trauma, which we explored in an optional section of our survey. 80% of the women living with HIV respondents chose to take part in this section.

MENTAL HEALTH AND HIV CARE

*"There was a period of time, about a year, **I went off my HIV meds because I was feeling passively suicidal.** Because of depression, I self-medicated with alcohol and drugs, which made being adherent to medications more difficult, as well as following up with doctor's appointments."*

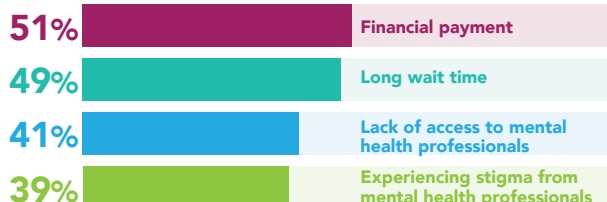
*"**Was in denial of diagnosis from 1988 until PCP pneumonia and near death in 1998...** Later after being on ART [Antiretroviral Therapy] and doing well, I again denied that I needed the medications and went off them until 2014 when I almost died a second time from PCP."*

*"I experience **depression and anxiety which sometimes interfere with my scheduling** and attending necessary medical appointments."*

COPING WITH MENTAL HEALTH ISSUES: More than half (56%) of respondents reported that mental health issues in their lives—chiefly related to depression and anxiety—had made it more difficult for them to address their HIV-related care needs. Several respondents mentioned that these mental health issues affected their adherence to taking their HIV medicines. Almost all (95%) sought professional care for their mental health needs. While 81% were ultimately able to get the care they needed, 40% reported encountering challenges to accessing mental healthcare.

COMMON BARRIERS TO ACCESSING MENTAL HEALTHCARE for women living with HIV

(of the 40% of women living with HIV who reported encountering challenges to accessing care for their mental health needs)



EXPERIENCES OF TRAUMA: 80% of respondents indicated that they had experienced trauma at some point in their lives. In many cases, respondents reported that they had experienced multiple traumas, including physical, verbal, and sexual violence; rape; childhood sexual abuse; domestic abuse; and exposure to family violence. Seven of eight transwomen respondents reported trauma that caused them to experience mental, emotional, or behavioral health problems. They described suffering from child abuse, inability to date or maintain personal intimate relationships as a result of being a former sex worker, and having suicidal thoughts. For the transwomen respondents, these mental health issues also made it harder for them to address their HIV care needs.



80%

of women living with HIV respondents reported experiencing trauma in their lives

TRAUMA EXPERIENCED BY WOMEN LIVING WITH HIV

*"Childhood psychological, physical, and psychosexual abuse. Poverty. **All the ongoing violations and trauma that have gone with being a female in our society/culture.** HIV diagnosis. AIDS diagnosis. AIDS Survivor Syndrome."*

*"**I have been molested, and physically, mentally, emotionally abused by guardians** that I was staying with growing up because my mom died when I was four. I was with some of the wrong people that cared less about me because I was supposed to be dead like she was."*

*"**I felt like dying.** I no longer wanted to be on this earth and felt like my kids would be better off without me. No longer wanted to take my meds."*

Awareness and Impact of U=U

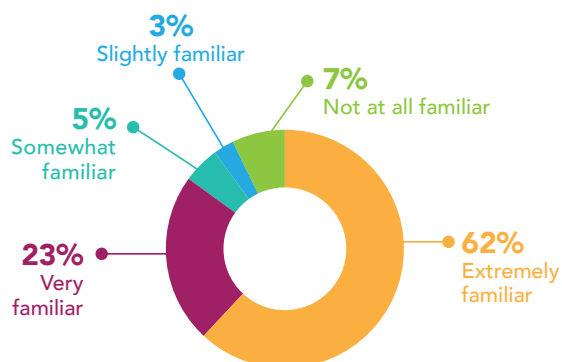
In recent years, the science proving that people who consistently take HIV medications and maintain viral suppression will not transmit HIV to their sex partners has been translated into an educational and anti-stigma communications and advocacy campaign, called “U=U” (Undetectable = Untransmittable). The Well Project was interested in knowing whether respondents were aware of U=U and, if so, what impact it has had on their lives.

85% of women living with HIV respondents were very or extremely familiar with the U=U message, 78% said they were very or extremely confident about the U=U message, and **72% said learning about U=U has had a tremendous or significant positive impact in their lives**. Two-thirds of respondents reported that their healthcare provider had never discussed U=U with them. Rather, women living with HIV learned about U=U from social media, conferences, and community-based and non-profit organizations, including The Well Project and Prevention Access Campaign, the originator of the U=U movement.

Awareness and Impact of U=U

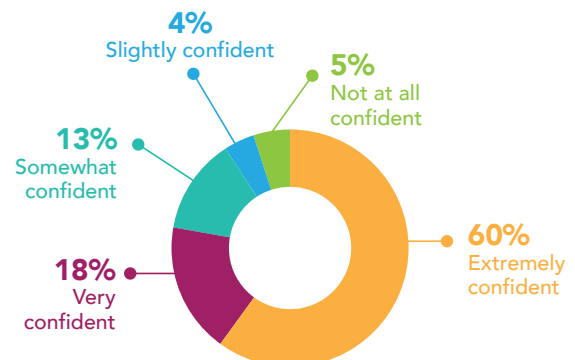
Women living with HIV respondents reported the following:

Familiarity with U=U

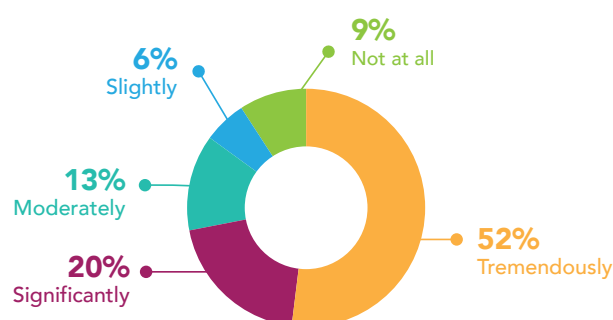


Confidence in U=U Message

(HIV cannot be sexually transmitted with an undetectable viral load)



U=U's Positive Impact on Their Lives



Heard about U=U from Healthcare Provider



Use and Assessment of The Well Project's Resources



While recognizing the demographic and experiential diversity of women living with HIV (including our survey respondents), The Well Project aims to provide resources that will enhance education, community-building, and advocacy among all of them. Therefore, it is important to know how women living with HIV have used The Well Project's resources and the impact our resources have had on their relationship to their HIV status and their overall health and well-being.

The Well Project offers a multitude of online resources, including:

- HIV Information: Library of Fact Sheets (English and Spanish) and Slide Sets
- *A Girl Like Me/Una Chica Como Yo* Blogs
- Treatment Advocacy Webinars
- Monthly E-newsletters; Weekly Email Updates
- Social Media (Facebook, Twitter, Instagram, YouTube)
- Women's Research Initiative on HIV/AIDS (WRI)
- Building H.O.P.E Outreach Video/Other Outreach Materials

VALUE OF USING THE WELL PROJECT'S RESOURCES: Respondents ranked the value of The Well Project's resources in helping them reach their overall goals to improve knowledge and health outcomes:

Respondents said The Well Project's resources were "extremely" and "very" valuable to them in the following ways:

84%

**Be more empowered
to advocate for myself**

75%

**Improve my
health outcomes**

81%

**Increase my knowledge
of HIV disease &
its treatments**

72%

**Prevent transmission of
HIV and other STIs to
myself or others**

78%

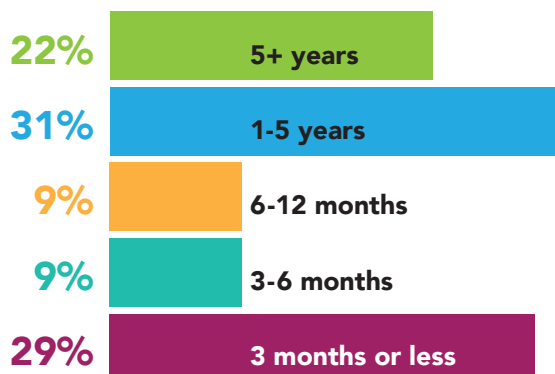
**Feel connected to a
community of support**

71%

**Improve my
relationship(s) with my
healthcare provider(s)**

DURATION AND FREQUENCY OF USE: 22% of women living with HIV have been using The Well Project's resources more than five years, 31% between one and five years, 9% six to 12 months, 9% three to six months, and 29% less than three months. More than 60% of the transwomen respondents were new to The Well Project and fell into the final category. About 6% of women living with HIV used The Well Project resources daily, 20% used them a few times per week, 22% used them a few times per month, and 19% used them a few times per year.

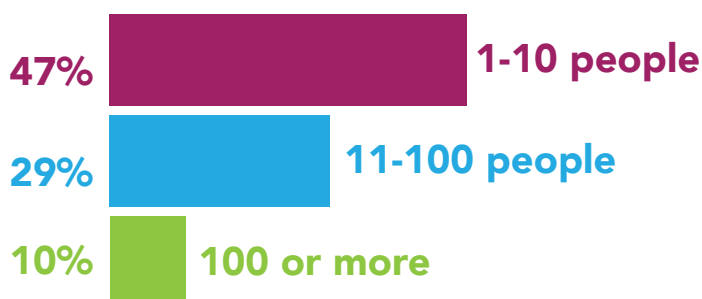
Duration of Using The Well Project's Resources



SHARING THE WELL PROJECT'S RESOURCES:

Sharing information is an important element of the education, connectedness, and advocacy trajectory The Well Project aims to engender among women living with HIV. 47% of survey respondents said that they regularly shared The Well Project's resources with one to 10 people in their lives during the year, 29% regularly shared with 11 to 100 people, and 10% regularly shared with more than 100 individuals.

Number of people with whom women living with HIV respondents share The Well Project's resources



ASSESSMENT OF THE WELL PROJECT'S RESOURCES: More than 90% of women living with HIV overall and 100% of transwomen reported that they were "very" (74%/90%) or "somewhat" (19%/10%) satisfied with The Well Project's resources. The **most rewarding finding** from the survey was that **98%** of respondents overall and **100%** of transwomen agreed that **"The Well Project recognizes and respects the cultural differences among its users, making its resources inclusive, equitable, and culturally responsive."**



98% Agree

"The Well Project recognizes and respects the cultural differences among its users, making its resources inclusive, equitable, and culturally responsive."

POSITIVE FEEDBACK

ABOUT THE WELL PROJECT

"It is already doing a great job. Since I fall under hearing handicapped category, I have noticed The Well Project webinar being hosted with slide shows and chat forum, and video with subtitles. Kudos!"

"I am so glad that The Well Project is doing research on women's health with HIV, since for many years it was all geared toward just men."

"I love this organization more than most I have encountered."

"I like A Girl like Me blog, which helps me to feel not so unique. Thanks for ALL you do here!"

"I am so grateful for the female focused HIV info you provide! The breastfeeding webinar has been incredibly helpful for so many of my clients!"

*"I LOVE your very existence, since HIV+ women in general have been invisible and ignored for way too long! Praise to you also, for political activity, and sharing that info. **THANK YOU!!!**"*

The Well Project has been providing online resources for the past 17 years and these survey data validate that our programming is having a notable impact on the women living with HIV who use our resources. An important facet of the survey was to solicit feedback on how we can further improve our programming and efforts to support women living with and vulnerable to HIV. Survey respondents offered a variety of suggestions and reflect some of our efforts that are currently in development.

- **Increase marketing and publicity for The Well Project**, including through broadcast media, social media, and advertising in print publications
- **Ensure that fact sheets address rural issues**
- **Ensure materials are printer-friendly**
- **Make The Well Project's resources available in multiple languages**

Impact of The Well Project's Resources

This year's survey included several questions to help us assess whether and how The Well Project's resources are having an impact on education, health and well-being, community connectedness, and advocacy among women living with HIV.

KNOWLEDGE: Respondents often initially access The Well Project's resources to increase their knowledge about HIV and the many ways it affects their lives as women. About two-thirds reported that The Well Project has had a significant impact on their knowledge of HIV treatment, how to connect with other women living with HIV, and aging/comorbidities.

KNOWLEDGE ABOUT HIV

Women living with HIV reported that The Well Project's resources increased their knowledge of:



69%

HIV
treatment



67%

How to connect
with other women
living with HIV



65%

HIV and
aging/other
comorbidities



64%

HIV
prevention



60%

HIV and
pregnancy



59%

How to navigate
care systems

"I have never before found information about women only."

ENGAGEMENT IN CARE: Respondents noted numerous ways in which engaging with The Well Project’s resources positively influenced their engagement in care. They reported that using The Well Project’s resources had helped them feel emboldened to actively engage with healthcare providers, ask more specific questions about HIV and women, and play a more active decision-making role about their own care. More than three-quarters of respondents reported that The Well Project’s resources helped them better appreciate the importance of medication adherence and take their HIV medication as prescribed.

ENGAGEMENT IN CARE

When asked about how The Well Project’s resources had influenced specific aspects of their engagement in care, women living with HIV responded they were **“somewhat” or “much” more likely to:**



81%

Talk with providers about medication options, concerns, and side effects



79%

Communicate effectively and advocate for myself with healthcare provider/s



79%

Talk with healthcare provider/s about how HIV affects women differently than men



76%

Take HIV medication regularly as prescribed



74%

Navigate care systems more effectively



62%

See healthcare provider/s regularly



55%

Talk with healthcare provider/s about PrEP

*“Thank you so much for being part of **the community that builds, teaches and shares information.** Thats what I call love.”*

SELF-CARE: Self-care is also an important aspect of living with HIV. Self-care is a phrase that refers to a range of strategies that individuals can use to mitigate the kinds of mental and physical health challenges that people living with HIV experience, such as chronic pain, stress, depression, and fatigue. We asked respondents to assess how using The Well Project's resources had influenced specific aspects of self-care related to their emotional well-being. Many participants noted that these resources had motivated them to better understand their own mental and emotional self-care needs. More than two-thirds of respondents reported that The Well Project's resources contributed to their actions to improve their physical, mental, and behavioral health.

SELF-CARE

When asked how The Well Project's resources had affected aspects of self-care related to their emotional well-being, women living with HIV responded they were **"somewhat" or "much" more likely to:**



72%

Eat healthy foods



71%

Accept only respectful, caring behavior from partners, family, and/or friends



69%

Try to get enough/good rest



67%

Seek out care for mental/emotional/behavioral health issues



66%

Seek out support for past or current violence or trauma



65%

Exercise or move regularly



64%

Practice safer sex

"I use the resources from The Well project to help me better explain to family and friends who do not understand the virus and the challenges I may face with being positive."

OUTLOOK ON LIVING WITH HIV: At The Well Project, we believe that a person's outlook on living with HIV is closely related to their quality of life. Based on the interconnectedness that we have seen between decreased stigma and isolation and increased hopefulness, connectivity, and advocacy, we asked respondents to assess The Well Project's influence on their perspectives about living with HIV. The vast majority of respondents reported that The Well Project resources influenced their outlook on living with HIV in positive ways, including engendering hope for the future and resisting stigma. More than three-quarters of respondents also reported feeling more valuable as a person and a sense of emotional well-being as a result of engaging with The Well Project.

OUTLOOK ON LIVING WITH HIV

When asked to assess The Well Project's influence on their outlook on living with HIV, women living with HIV responded they were **"somewhat" or "much" more likely to:**



83%

Feel hopeful about the future



79%

Feel valuable as a person



76%

Feel a sense of emotional well being



74%

Experience less HIV self-stigma



72%

Experience less HIV stigma from others



70%

Feel comfortable disclosing my HIV status to others

64%

Feel less isolated due to my HIV status



*"I would like to thank you people for working hard to **make life better for women.** All you are doing is excellent!!!!"*

CONNECTION AND COLLABORATION: The Well Project’s work over the past 17 years has demonstrated how damaging social isolation can be for women living with HIV. In 2009, The Well Project debuted our *A Girl Like Me* blog, which was developed to help foster community among women living with HIV both online and within the community. In the 10 years since, *A Girl Like Me* and The Well Project have played a vital role in women’s paths toward improved connection and collaboration. In the interest of quantifying how forms of connection beyond a robust online support community were manifesting, The Well Project included several questions in the survey about connection and collaboration. More than three-quarters of respondents reported that The Well Project has made them somewhat or much more likely to connect to their community, collaborate with others, and engage with peer support groups.

CONNECTION AND COLLABORATION

When asked to assess The Well Project’s influence on connecting to a community, women living with HIV responded they were **“somewhat”** or **“much”** more likely to:



80%

Collaborate with
other women
living with HIV



77%

Connect to a community
or network of women
living with HIV



76%

Connect to my
local community



71%

Engage with support
groups for women
living with HIV

*“Great resource and great people. I got to meet some of the staff at USCA 2018 in Orlando, and **everyone was so kind and welcoming**, and very happy that they are able to **provide a resource that helps people from so far away**. Keep up the good work!”*

ADVOCACY: Users of The Well Project have anecdotally reported over the years that their engagement with our resources has helped increase or develop their advocacy-related efforts. In order to gain a deeper understanding of this impact, we included several questions in the survey about the ways in which The Well Project impacted their advocacy development. 80% of respondents said they were more likely to advocate for themselves and others living with HIV as a result of interacting with The Well Project and our resources. More than two-thirds were also more likely to join an advisory board or take a leadership role at an HIV organization.

ENGAGE IN ADVOCACY

When asked to assess The Well Project's influence on their advocacy development, women living with HIV responded they were **"somewhat" or "much" more likely to:**



81%

Advocate for the needs of others living with HIV



80%

Advocate for my own needs when I seek care and support



69%

Join an advisory board for an HIV organization



67%

Take on a leadership role in an HIV advocacy organization



66%

Speak at an HIV-related conference



64%

Engage with media about HIV-related issues

62%

Join an HIV planning council



*"I have been a part of The Well Project family for nine years. **It has helped me learn so many things and groomed me into a fine advocate.** I will continue to remain with The Well Project till my last breath."*

Conclusion



Important Takeaways about the Experiences of Women Living with HIV

Data from The Well Project's survey illustrate how women living with HIV have made significant progress in some areas but continue to face obstacles in others. Nearly all of the women living with HIV who participated in this survey are engaged in HIV care, taking effective HIV medications, and experiencing viral suppression, which is extremely positive. At the same time, these women face high levels of stigma inside and outside of the healthcare system, past and/or current violence and trauma, and behavioral health issues that complicate their ability to access and maintain comprehensive care. Moreover, as women age with HIV, many experience comorbidities, coinfections, and complications that result from the confluence of long-term HIV disease, HIV medication use, and processes of normal aging. Our data show that women's physical and mental health needs sometimes go unmet, which further demonstrates how important it is to coordinate and integrate physical and behavioral health, as well as social services for this population. This is particularly true for women with low levels of employment and modest incomes who may depend on public support systems to provide much of what they need.

TOP LEARNINGS OF THE EXPERIENCES OF WOMEN LIVING WITH HIV

TRAUMA

80% indicated that they experienced **TRAUMA** at some point in their lives

DISCLOSURE

72% reported feeling most comfortable **DISCLOSING THEIR STATUS** to other people living with HIV

U=U

72% reported that **U=U** is having a tremendously or significantly positive impact on their lives

STIGMA

69% reported experiencing **STIGMA** in their personal lives, **61%** in healthcare settings, and **60%** reported experiencing self-stigma

HEALTH CONDITIONS

65% reported experiencing **OTHER SERIOUS HEALTH CONDITIONS**, in addition to HIV

Important Takeaways about The Well Project's Impact on Women Living with HIV

Data from this survey also confirm The Well Project's programs continue to have a significant impact on the health and well-being of women living with HIV and that we provide unique and valuable services that impact their daily lives. While health concerns are central for women living with HIV, they are not the only issues of importance. This survey reveals The Well Project is especially strong in connecting women to one another and developing advocacy skills, and that social support and community engagement impact women's lives in positive ways.

Women often come to The Well Project to access information about the many aspects of their lives and report that our resources help them increase their knowledge of women-specific topics that are not

addressed elsewhere. Based on this knowledge base, women increase their engagement in care, are able to better address their needs, and connect to a global community of "girls like them," with whom they can share experiences and join forces to support one another. Becoming part of an empowered community enhances their self-esteem and paves a path for them to become advocates for themselves, their families, and others in their communities.

***"Keep motivating. Keep inspiring.
Keep saving lives. Keep bringing smiles."***

TOP LEARNINGS ABOUT THE WELL PROJECT'S IMPACT ON WOMEN LIVING WITH HIV

INCLUSION

98% agreed that "The Well Project recognizes and respects the cultural differences among its users, making its resources inclusive, equitable, and culturally responsive"

ADVOCACY

81% said using The Well Project's resources made them more likely to advocate for others living with HIV

CONNECTION

80% said using The Well Project's resources made them more likely to collaborate with other women living with HIV

SELF-ESTEEM

79% said using The Well Project's resources made them feel more valuable as a person and 74% felt less self-stigma

ENGAGEMENT

79% said using The Well Project's resources made them more likely to communicate effectively with healthcare providers, and 76% more likely to take their medications as prescribed

Looking Ahead

Based on the feedback and recommendations we received in the survey, The Well Project will continue to maintain our excellent existing resources and programming, as well as identify and address gaps, expand our reach, and deepen our impact among diverse communities of women. We will also continue to build upon our advocacy and leadership development, which has grown exponentially in the past few years. As such, the survey findings described in this report validate the priorities that The Well Project has identified to drive our programming over the next five years:



Together, We Are...

The Well Project remains deeply committed to reaching all women where they are and providing them with the information, resources, and support they need. We are committed to reducing HIV stigma and ensuring women living with HIV are not just surviving, but thriving. ***We are stronger together, and working in collaboration, we will continue to build partnership, leadership, and provide tools to change the course of the HIV epidemic...one woman at a time.***



Join us.

Together, we can change the course of the HIV epidemic...
one woman at a time.

Visit www.thewellproject.org to access:

▶ **#information** ▶ **#community** ▶ **#advocacy**



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kmartel@thewellproject.org.*



Knowledge

Empower

Support

Improved Health
Outcomes

Connect